

113TH CONGRESS
2D SESSION

H. R. 594

AN ACT

To amend the Public Health Service Act relating to Federal research on muscular dystrophy, and for other purposes.

1 *Be it enacted by the Senate and House of Representa-*
2 *tives of the United States of America in Congress assembled,*

1 **SECTION 1. SHORT TITLE.**

2 This Act may be cited as the “Paul D. Wellstone
3 Muscular Dystrophy Community Assistance, Research and
4 Education Amendments of 2014”.

5 **SEC. 2. INITIATIVE THROUGH THE DIRECTOR OF THE NA-**
6 **TIONAL INSTITUTES OF HEALTH.**

7 Section 404E of the Public Health Service Act (42
8 U.S.C. 283g) is amended—

9 (1) in subsection (a)(1)—

10 (A) by striking “Muscoskeletal” and in-
11 serting “Musculoskeletal”; and

12 (B) by inserting “Becker, congenital mus-
13 cular dystrophy, limb-girdle muscular dys-
14 trophy,” after “Duchenne,”;

15 (2) in subsection (b)—

16 (A) in paragraph (2)—

17 (i) by striking “genetics,” at the sec-
18 ond place it appears; and

19 (ii) by inserting “cardiac and pul-
20 monary function, and” after “imaging,”;
21 and

22 (B) in paragraph (3), by inserting “and
23 sharing of data” after “regular communica-
24 tion”;

25 (3) in subsection (d)—

26 (A) in paragraph (2)—

1 (i) in the matter preceding subpara-
2 graph (A), by striking “15” and inserting
3 “18”; and

4 (ii) in subparagraph (A)—

5 (I) by striking “and the Food
6 and Drug Administration” and insert-
7 ing “, the Food and Drug Administra-
8 tion, and the Administration for Com-
9 munity Living”;

10 (II) by inserting “and adults”
11 after “children”; and

12 (III) by striking “such as the De-
13 partment of Education” and inserting
14 “including the Department of Edu-
15 cation and the Social Security Admin-
16 istration”; and

17 (B) in paragraph (4)(B), by inserting “,
18 but shall meet no fewer than two times per cal-
19 endar year” before the period; and

20 (4) in subsection (e)—

21 (A) in paragraph (1)—

22 (i) in the matter preceding subpara-
23 graph (A), by striking “through the na-
24 tional research institutes” and inserting
25 “through the agencies represented on the

Coordinating Committee pursuant to subsection (d)(2)(A)”; and

(ii) in subparagraph (A)—

(I) by inserting “public services,” before “and rehabilitative issues”; and

(II) by inserting “, studies to demonstrate the cost-effectiveness of providing independent living resources and support to patients with various forms of muscular dystrophy, and studies to determine optimal clinical care interventions for adults with various forms of muscular dystrophy” after “including studies of the impact of such diseases in rural and underserved communities”; and

(B) in paragraph (2)(D), by inserting after “including new biological agents” the following: “and new clinical interventions to improve the health of those with muscular dystrophy”.

SEC. 3. SURVEILLANCE AND RESEARCH REGARDING MUSCULAR DYSTROPHY.

The second sentence of section 317Q(b) of the Public Health Service Act (42 U.S.C. 247b–18(b)) is amended by inserting before the period the following: “and, to the

1 extent possible, ensure that data be representative of all
2 affected populations and shared in a timely manner”.

3 **SEC. 4. INFORMATION AND EDUCATION.**

4 Section 5(c) of the Muscular Dystrophy Community
5 Assistance, Research and Education Amendments of 2001
6 (42 U.S.C. 247b–19(c)) is amended—

7 (1) in paragraph (2)—

8 (A) by inserting “for pediatric and adult
9 patients, including acute care considerations,”
10 after “issuance of care considerations”;

11 (B) by inserting “various” before “other
12 forms of muscular dystrophy”; and

13 (C) by striking “and” at the end;

14 (2) by redesignating paragraph (3) as para-
15 graph (4);

16 (3) by inserting after paragraph (2) the fol-
17 lowing:

18 “(3) in developing and updating care consider-
19 ations under paragraph (2), incorporate strategies
20 specifically responding to the findings of the national
21 transitions survey of minority, young adult, and
22 adult communities of muscular dystrophy patients;
23 and”; and

1 (4) in paragraph (4), as redesignated, by insert-
2 ing “various” before “other forms of muscular dys-
3 trophy”.

Passed the House of Representatives July 28, 2014.

Attest:

Clerk.

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